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Congress of the United States
House of Representatives

Washington, DC 20515

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The Honorable Denny Rehberg
Chairman
Subcommittee on Labor, HHS & Education
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS & Education
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairman Rehberg and Ranking Member DeLauro:

Thank you for your previous support of the National ALS Registry. I respectfully request that during consideration of the FY 2012 Labor/HHS Appropriations Act, the Subcommittee include \$10 million in funding to continue the National ALS Registry at the Centers for Disease Control and Prevention. This is a programmatic request that would build upon prior appropriations and enable the CDC to continue vital work underway to combat, prevent, and find a treatment for Lou Gehrig's Disease.

Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis, ALS) is a particularly cruel disease that destroys a person's ability to control muscle movement. As the disease progresses, its victims become trapped inside a body they no longer can control; unable to walk, talk, breathe or even blink an eye. There is no effective treatment for ALS, no known cause and no cure. The disease can strike anyone, regardless of their age, gender, race or nationality. And it is always fatal - in an average of two to five years following diagnosis.

In 2008, the House passed authorization legislation, the ALS Registry Act, by an overwhelming 415-2 vote and the President signed the bill into law (P.L. 110-373) on October 8, 2008. With Congress' previous appropriation support, the CDC and Agency for Toxic Substances and Disease Registry (ATSDR) have begun to implement the Registry, including collecting ALS Medicare, Medicaid and VA data. It also has enabled the Agency to launch an online "web portal" which people with ALS can access to enroll in the Registry. The web portal was launched in October 2010 and patients from around the country currently are enrolling.

Funding is needed in FY 2012 to continue the Registry, coordinate federal efforts, help people enroll in the Registry and conduct outreach activities to identify cases in every state. Funding is also needed to begin to link this powerful tool to epidemiologic studies and research into biomarkers, risk factors, and clinical studies to identify new treatments.

I urge you to support this programmatic request and include \$10 million in the FY 2012 LHHS Appropriations Act to continue the National ALS Registry. Thank you for your consideration.

Sincerely,



Bruce Braley